Hospital Registry Conduct Active Follow-Up Use Case

Version 1.0

Prepared by: NPCR-AERRO Central Cancer Registry Workgroup

NPCR-AERRO Technical Development Team

Centers for Disease Control and Prevention

National Center for Chronic Disease Prevention and Health Promotion

Division of Cancer Prevention and Control

National Program of Cancer Registries

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Table of Contents

General Information

1. Use Case ID

HUC 3.1

2. Use Case Name

Conduct Active Follow-Up

3. Description

The National Program of Cancer Registries (NPCR) does not require registries to perform active follow-up. This use case is provided for those who perform follow-up to meet Commission on Cancer, SEER, or Hospital Cancer Committee requirements or are considering performing active follow-up.

Conducting active follow-up is the process of obtaining updated information annually regarding a patient's health status to ensure continued medical surveillance. This use case provides the steps taken to conduct active follow-up and is intended for hospital registrars, physicians, and information technology system professionals in hospitals and physician offices.

4. Actors

- Cancer registry (CR) software
- Registrar
- Respondent (clinician and/or patient)

5. Definitions

None.

Conduct Active Follow-Up

Note: Diagrams for this use case are in Appendix A and Appendix B.

1.0 Preconditions

A set of conditions that must be met before the activities described in the use case can begin.

Passive follow-up using facility encounters to update vital status and cancer status must be performed. (HUC1.4 – Perform Casefinding and Passive Follow-up.) This use case ensures that patients interacting with the hospital will have their follow-up status updated automatically.

If a registry does not have electronic casefinding and passive follow-up implemented in their facility, the registrar must perform follow-up activities within the facility as a part of this use case.

Criteria for selecting cases for follow-up have been installed in the registry software.

2.0 Post Condition

A set of conditions that must be met after the activities described in the use case have been completed.

Vital status, cancer status, and date of last contact have been updated.

3.0 Priority

Describes the importance and sequence of the use case in the overall activities of the cancer registry.

To be determined.

4.0 Frequency of Use

Describes how often the activities in the use case take place.

Patients must be followed up annually, which requires registries to conduct active follow-up every month.

5.0 Normal Course of Events

Describes the specific steps taken to perform the activity in the use case.

Normal refers to the steps that are taken when everything goes according to routine procedures. Problems and exceptions are described in section 6, Alternative Course.

Business rules are statements that describe a decision that must be made and agreed to by those involved in the activity. In the context of this document, a business rule describes the decision that needs to be made, and in some circumstances provides a recommendation; in others, options for consideration and use.

Software requirements are statements that describe the functionality of the software that is required or recommended.

5.1 This use case begins when CR software selects abstracts that meet the criteria for active follow-up. [BR01, BR02, BR03, BR04, BR05] [SR01]

BR	Business Rule	Purpose	Remarks
01	Patients must be followed up annually, which requires registries to conduct active follow-up every month.	To meet CoC standards.	See the most recent edition of the CoC's *Facility Oncology Registry Data Standards (FORDS)* for further discussion on follow-up standards.
02	At a minimum, the registrar should use the American College of Surgeons (ACoS) Commission on Cancer rules regarding active follow-up.	To ensure follow-up information needed for analysis, research and reporting are collected.	See the most recent edition of the CoC's *Facility Oncology Registry Data Standards (FORDS)* for further discussion on follow-up standards.
03	The registrar should continue to conduct follow-up for cases marked "lost to follow-up," even if more than 15 months have passed.		Lost to follow-up is when the status of the patient has not been confirmed more than 15 months after the date of last contact. See Appendix C for a discussion of patients lost to follow-up.
04	The registrar may begin the follow-up process on cases prior to the 12-month standard.	To minimize postage costs and resources needed for sorting.	
05	In registries not using HUC 1.4 Perform Casefinding and Passive Follow-Up, the registrar must review facility information to identify patients who have interacted with the facility during the follow-up period.		The NPCR-AERRO use cases provide for automated follow-up for patients who use hospital services. Registries that have not implemented these use cases must perform the follow-up process manually.

SR	Software Requirement	Purpose	Remarks
01	CR software should allow registrars to specify criteria for abstract selection: • 12 or more months from the date of last contact. • Custom selection based on specific criteria.	To ensure that cases needing follow-up can be identified accurately.	Example of custom follow-up selection: • Female breast cancers, stage I and II, still alive, diagnosed at age 40–49 within the last 15 years • Include patients from the previous "x" months where a response hasn't been received

5.2 CR software performs patient linkage with death files and finds no match. [SR02]

Note: Refer to the NPCR-AERRO *CCRUC 1.4 Perform Patient Linkage* and *CCRUC 2.2 Perform External Linkage to Improve Data* use cases. Refer to NAACCR Death Clearance Practice Standards (to be announced) for further information on using death certificates in follow-up activities.

SR	Software Requirement	Purpose	Remarks
02	CR software should perform patient linkage with death files from state vital records or the Social Security Administration's National Death Index.		

5.3 Registrar selects the appropriate follow-up form type. [BR06]

BR	Business Rule	Purpose	Remarks
06	CR software should provide a variety of follow-up letter types, including: • Individual patient follow-up letter to the clinician or patient • Multiple patient follow-up form to a clinician/clinic		A list of patients to a single person may be useful when follow-up responses will be entered online using a secure Web-based follow-up system, or when minimal follow-up information is collected.

5.4 CR software creates the follow-up form. [BR07, BR08, BR09] [SR03, SR04, SR05, SR06]

BR	Business Rule	Purpose	Remarks
07	The follow-up form should include information on the rationale and importance of current patient follow-up.		
08	The follow-up notification system or form should include, at a minimum, the following information to identify the patient: • Patient name • Date of birth • Social Security number (to doctor or hospital only) • Current address • Phone number • Primary site • Date of diagnosis • Date of last contact • Name of primary physician • Primary contact information		
09	At a minimum, data items to be requested for the physician to complete should include: • Current patient address • Phone number • Primary physician • Primary patient contract • Date of last contact (doctor or hospital) • Vital status • Cancer status • Recurrence type • Recurrence date Subsequent date and treatment type also may be collected.		CoC-required follow-up data includes: • Cancer status • Date of first recurrence • Date of last contact or death • Following registry • Follow-up source • Type of first recurrence • Vital status Follow-up should also be performed to obtain data on the full first course treatment. See the most recent edition of the CoC's *Facility Oncology Registry Data Standards (FORDS)* for further discussion on follow-up standards.

SR	Software Requirement	Purpose	Remarks
03	CR software should allow registrars to customize data items to include or exclude on the request form (both data items from the registry and data items that require completion)	To ensure complete reporting of needed information.	Follow-up may be performed for specific studies that may wish to obtain additional information about the patient.
04	CR Software should provide options for printed format, including Microsoft Word, Microsoft Excel, and Adobe PDF.		
05	CR software should provide a mail-merge function to generate a variety of follow-up letters (to the patient, to physicians, or to patient contacts) using a batch method. The type of letter printed for each patient is determined by the coded "Follow-up Method" field in the patient's abstract.		
06	CR Software should provide an option for printing in order by physician, clinic, medical record number, or alphabetic.		

5.5 Registrar electronically notifies follow-up contact (physician or patient) that follow-up information is needed. [BR10, BR11, BR12]

Note: This is future best practice and requires physician acceptance, security and privacy issues resolved, and technology upgrades. The current method of sending printed forms (described in 6.0 Alternate Course of Events) most likely will be the most common method of performing follow-up for the short to middle term. Need to maintain accurate e-mail addresses.

BR	Business Rule	Purpose	Remarks
10	Registrar may send the follow-up form to the patient or to the physician.	To improve the accuracy and response rate.	The facility's Cancer Committee may have a policy on whether the patient can be the follow-up contact.
11	Registrar must obtain and maintain an accurate e-mail address for physicians.	To ensure accurate notification of follow-up.	
12	Security and privacy measures must be followed.	To ensure private information is not released to others.	

5.6 Respondent (physician/clinic staff) logs in to the CR software follow-up notification system. [SR07]

SR	Software Requirement	Purpose	Remarks
07	The follow-up notification system should be maintained on a secure Web site that is password protected and has a short duration for access.	To ensure patient privacy.	

5.7 CR software displays follow-up data items for the respondent (physician/clinic staff). [SR08]

SR	Software Requirement	Purpose	Remarks
08	CR software should display information from BR06 and BR07.		

5.8 Respondent (physician/clinic staff) reviews the displayed information, makes revisions as appropriate, and enters follow-up information. [BR13]

BR	Business Rule	Purpose	Remarks
13	Respondent should confirm or change information listed in BR06.		

5.9 CR software stores information from the follow-up entry system in a separate table. [SR09]

SR	Software Requirement	Purpose	Remarks
09	The identity of the user making the change and the date of the submission should be stored.		

5.10 The registrar validates information.

5.11 CR software updates the cancer registry abstract. [SR10, SR11, SR12]

SR	Software Requirement	Purpose	Remarks
10	The CR software should update data elements as determined in step 5.4.		See step 5.4 and supporting BR06 and BR07 for a list of data items.
11	Date of last contact should be updated with the date of submission of the follow-up information.		
12	The Follow-up Source field also should be updated automatically to indicate that the patient entered the updated information.		

5.12 The registrar updates the contact "first choice" to be used for the next follow-up activity.

5.13 End of use case.

6.0 Alternative Course of Events

Numbering in this section refers to its associated step above in section 5, Normal Course of Events.

5.2a CR software performs patient linkage with death files and displays information on matching patients. [SR13]

SR	Software Requirement	Purpose	Remarks
13	CR software should display matched information from the death certificate alongside the patient's abstract.		

5.2b The registrar reviews the displayed information.

5.2b.1 The registrar accepts the death certificate information and the CR software updates the abstract.

5.2.b.1.1 If the cancer status is not known, the process continues with step 5.3.

5.2.b.1.2 If the cancer status is known, the use case ends.

5.2b.2 The registrar rejects the death certificate information and the process continues with step 5.3.

5.5a The registrar mails a printed follow-up form to the physician [BR10, BR12] and the process continues with step 5.6.

5.6a The respondent (physician/clinic staff) completes the paper follow-up form and returns it to the cancer registry. [BR12]

Note: This covers all of the steps required for performing follow-up using printed forms.

5.6b The registrar enters information from the printed follow-up form into the abstract.

5.6c The registrar scans and archives the paper follow-up form.

7.0 Business Rules and Software Requirements

A statement that describes a decision that must be made and agreed to by those involved in the activity. In the context of this document, a business rule describes the decision that needs to be made, and in some circumstances provides a recommendation; in others, options for consideration and use.

Business rules for this use case are presented under the step to which they apply.

Software requirements are identified in the context of enhancing and improving current cancer registry software. They are not a complete requirements list from which a new software package can be developed.

BR	Business Rule	Purpose	Remarks
01	Patients must be followed up annually, which requires registries to conduct active follow-up every month.	To meet CoC standards.	See the most recent edition of the CoC's *Facility Oncology Registry Data Standards (FORDS)* for further discussion on follow-up standards.
02	At a minimum, the registrar should use the American College of Surgeons (ACoS) Commission on Cancer rules regarding active follow-up.	To ensure follow-up information needed for analysis, research and reporting are collected.	See the most recent edition of the CoC's *Facility Oncology Registry Data Standards (FORDS)* for further discussion on follow-up standards.
03	The registrar should continue to conduct follow-up for cases marked "lost to follow-up," even if more than 15 months have passed.		Lost to follow-up is when the status of the patient has not been confirmed more than 15 months after the date of last contact. See Appendix C for a discussion of patients lost to follow-up.
04	The registrar may begin the follow-up process on cases prior to the 12-month standard.	To minimize postage costs and resources needed for sorting.	
05	In registries not using HUC 1.4 Perform Casefinding and Passive Follow-Up, the registrar must review facility information to identify patients who have interacted with the facility during the follow-up period.		The NPCR-AERRO use cases provide for automated follow-up for patients who use hospital services. Registries that have not implemented these use cases must perform the follow-up process manually.

BR	Business Rule	Purpose	Remarks
06	CR software should provide a variety of follow-up letter types, including: • Individual patient follow-up letter to the clinician or patient • Multiple patient follow-up form to a clinician/clinic		A list of patients to a single person may be useful when follow-up responses will be entered online using a secure Web-based follow-up system, or when minimal follow-up information is collected.
07	The follow-up form should include information on the rationale and importance of current patient follow-up.		
08	The follow-up notification system or form should include, at a minimum, the following information to identify the patient: • Patient name • Date of birth • Social Security number (to doctor or hospital only) • Current address • Phone number • Primary site • Date of diagnosis • Date of last contact • Name of primary physician • Primary contact information		

BR	Business Rule	Purpose	Remarks
09	At a minimum, data items to be requested for the physician to complete should include: • Current patient address • Phone number • Primary physician • Primary patient contract • Date of last contact (doctor or hospital) • Vital status • Cancer status • Recurrence type • Recurrence date Subsequent date and treatment type also may be collected.		CoC-required follow-up data includes: • Cancer status • Date of first recurrence • Date of last contact or death • Following registry • Follow-up source • Type of first recurrence • Vital status Follow-up should also be performed to obtain data on the full first course treatment. See the most recent edition of the CoC's *Facility Oncology Registry Data Standards (FORDS)* for further discussion on follow-up standards.
10	Registrar may send the follow-up form to the patient or to the physician.	To improve the accuracy and response rate.	The facility's Cancer Committee may have a policy on whether the patient can be the follow-up contact.
11	Registrar must obtain and maintain an accurate e-mail address for physicians.	To ensure accurate notification of follow-up.	
12	Security and privacy measures must be followed.	To ensure private information is not released to others.	
13	Respondent should confirm or change information listed in BR06.		

SR	Software Requirement	Purpose	Remarks
01	CR software should allow registrars to specify criteria for abstract selection: • 12 or more months from the date of last contact. • Custom selection based on specific criteria.	To ensure that cases needing follow-up can be identified accurately.	Example of custom follow-up selection: • Female breast cancers, stage I and II, still alive, diagnosed at age 40–49 within the last 15 years • Include patients from the previous “x” months where a response hasn’t been received
02	CR software should perform patient linkage with death files from state vital records or the Social Security Administration’s National Death Index.		
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04	CR Software should provide options for printed format, including Microsoft Word, Microsoft Excel, and Adobe PDF.		
05	CR software should provide a mail-merge function to generate a variety of follow-up letters (to the patient, to physicians, or to patient contacts) using a batch method. The type of letter printed for each patient is determined by the coded "Follow-up Method" field in the patient's abstract.		

SR	Software Requirement	Purpose	Remarks
06	CR Software should provide an option for printing in order by physician, clinic, medical record number, or alphabetic.		
07	The follow-up notification system should be maintained on a secure Web site that is password protected and has a short duration for access.	To ensure patient privacy.	
08	CR software should display information from BR06 and BR07.		
09	The identity of the user making the change and the date of the submission should be stored.		
10	The CR software should update data elements as determined in step 5.4.		See step 5.4 and supporting BR06 and BR07 for a list of data items.
11	Date of last contact should be updated with the date of submission of the follow-up information.		
12	The Follow-up Source field also should be updated automatically to indicate that the patient entered the updated information.		
13	CR software should display matched information from the death certificate alongside the patient's abstract.		

8.0 Exceptions

None.

9.0 Includes

Refer to the NPCR-AERRO CCRUC 1.4 *Perform Patient Linkage Use Case* and CCRUC 2.2 *Perform External Linkage to Improve Data Use Case* for use cases relating to step 5.4.

10.0 Special Requirements

None.

11.0 Assumptions

This use case is based on the following assumptions:

- It is being developed following the HIPAA rules and regulations.
- The software is time-sensitive; hospitals and registries follow a strict deadline for receipt of records and reports.

12.0 Notes and Issues

None.

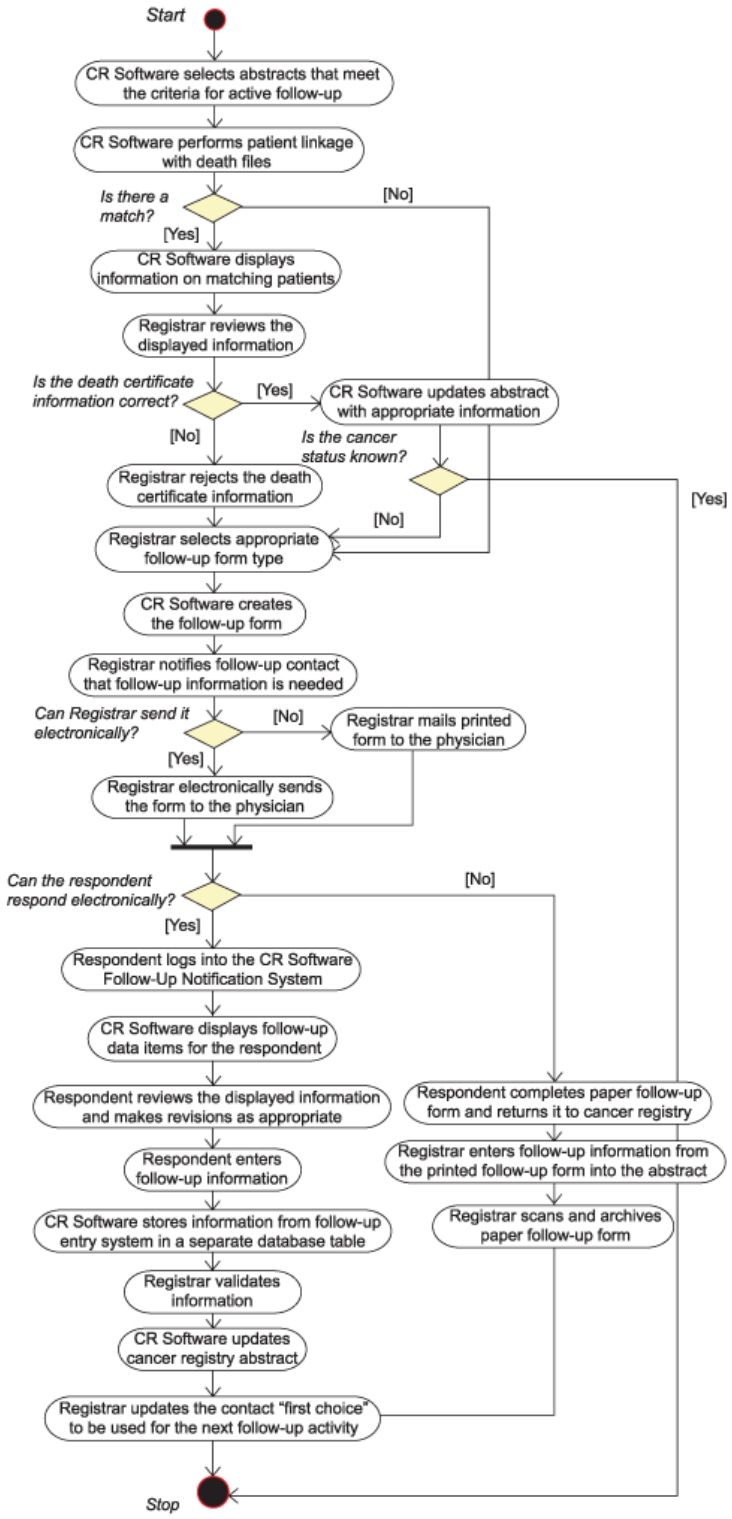
13.0 References

Gress D. Monitoring Patient Outcome: Follow-up. In: Hutchinson C. et al, Editors. *Cancer Registry Management: Principles and Practices, 2nd Edition.* DuBuque (IA): Kendall/Hunt, 2007: 185–198.

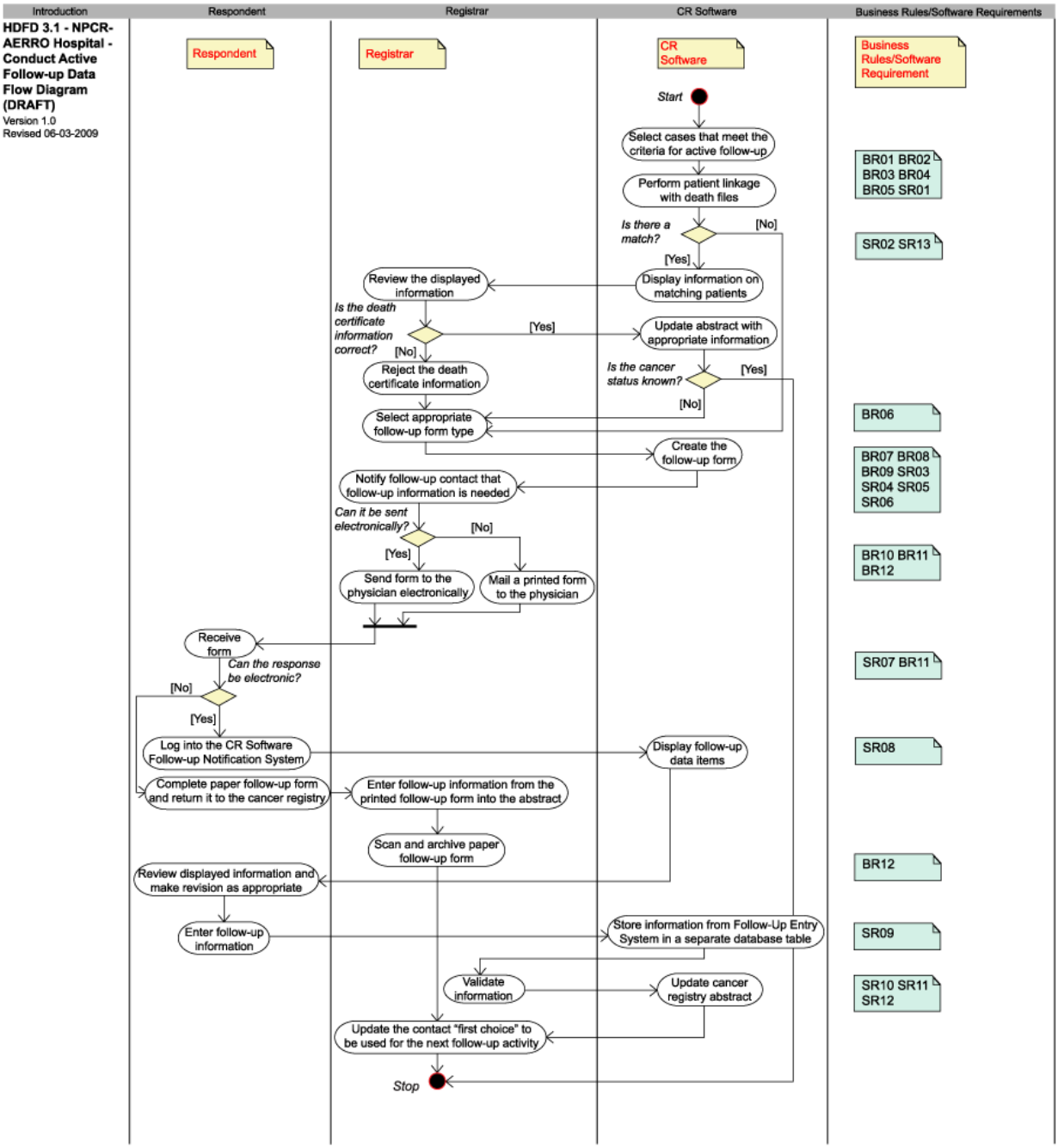
American College of Surgeons' Commission on Cancer. *Facility Oncology Registry Data Standards, 2002,* Revised for 2007.

Appendix A: Conduct Active Follow-Up Workflow Diagram

HWFD 3.1 - NPCR-AERRO Hospital: Conduct Active Follow-Up Workflow Diagram (DRAFT)
Version 1.0
Revised: 06-03-2009



Appendix B: Conduct Active Follow-Up Data Flow Diagram



Appendix C: Lost to Follow-Up

Lost-to-follow-up are Commission on Cancer (CoC) standards (3.4 and 3.5) that are part of the approval process for the hospital's cancer registry and cancer program. It states:

- **Standard 3.4:** An 80% follow-up rate is maintained for all eligible analytic patients from the cancer registry reference data.

- **Standard 3.5:** A 90% follow-up rate is maintained for all eligible analytic patients diagnosed within the last 5 years, or from the cancer registry reference date, whichever is shorter.

The CoC standard provides a three-month window for the registrar to obtain the required follow-up information before the case is counted against the registry in the follow-up calculation.

A lost-to-follow-up status should not to be confused with registry procedures for performing follow-up, as it has no bearing on sending follow-up letters or other methods to obtain follow-up. A registrar should not remove the case from follow-up procedures after the three-month window has passed; the case should be included as long as there is another source to try.

When all patient-specific options have been exhausted, the registrar should perform follow-up on these cases routinely through death indices and consider contacting the most recent physician again for any follow-up information.

Appendix D: Data Elements for Follow-up

The follow-up notification system or form should include, at a minimum, the following information to identify the patient:

- Patient name
- Date of birth
- Social Security number (to doctor or hospital only)
- Current address
- Phone number
- Primary site
- Date of diagnosis
- Date of last contact
- Name of primary physician
- Primary contact information

At a minimum, data items to be requested for the physician to complete should include:

Note: Subsequent date and treatment type also may be collected.

- Current patient address
- Phone number
- Primary physician
- Primary patient contract
- Date of last contact (doctor or hospital)
- Vital status
- Cancer status
- Recurrence type
- Recurrence date

CoC required follow-up data includes:

Note: Follow-up should also be performed to obtain data on the full first course treatment. See the most recent edition of the CoC's *Facility Oncology Registry Data Standards (FORDS)* for further discussion on follow-up standards.

- Cancer status
- Date of first recurrence
- Date of last contact or death
- Following registry
- Follow-up source
- Type of first recurrence
- Vital status

Use Case Administrative Information

1. Use Case History

Version 1.0 presented to the NPCR-AERRO Workgroup.

2. Created By

- NPCR-AERRO Hospital Workgroup
- NPCR-AERRO Technical Development Team

3. Date Created

January 17, 2008

4. Last Updated By

MA, WKS

5. Date Last Updated

July 13, 2009

Revision History

Name	Date	Reason for Changes	Version
MA	1/17/08	Created the new use case	0.01
WKS	3/24/08	Added information about CoC follow-up standards	0.02
MA, WKS	7/3/08	Modified the use case steps	0.03
Hospital Workgroup	7/22/08	Reviewed use case	0.04
WKS, MA	7/31/08	Modified and formatted the use case	0.05
MA	1/23/09	Formatting changes and final review	1.0
WKS	5/19/09	Updated business rules	1.0
WKS, MA	5/21/09	Updated precondition	1.0
MA	5/22/09	Formatting changes	1.0
MA	6/9/09	Published	1.0
WKS, MA	7/13/09	Updated after clearance comments	1.0